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ABSTRACT

This guide gives youth with disabilities and their families an overview of some of the major elements of the transition planning process. It introduces families to the adult service system that will provide supports and services after high school. Each chapter is intended to encourage families to be proactive in the planning process. The workbook format is designed to assist in formulating strategies, recording issues, and documenting progress. Individual sections address: an overview of the transition process; development of personal visions of the future; program planning--the role of parents and students on the transition team; case management; preparing for and participating in the Individual Service Plan meeting; vocational education planning; the Division of Rehabilitation Services; types of employment; residential options; preparing for transition to adult health care services; health care skills; estate planning; and the life planning process. (DB)

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BEGIN THE BETWEEN

Planning for the Transition from High School to Adult Life

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BEGIN THE BETWEEN

Planning for the Transition from High School to Adult Life

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Introduction

Welcome to the "Between" – the transition from high school to adult independent living and the opportunity to look at life-long goals, dreams, and visions.

This guide gives youth with disabilities and their families an overview of some of the major elements of the transition planning process. It introduces families to the adult system that will provide supports and services after high school. Each chapter enables families to be proactive in the planning process. They are encouraged to use this workbook to formulate strategies, record issues, and document their progress.

The issues addressed in this guide have been identified by students, parents and educators as global transition concerns. Because the specific needs of individuals vary, each youth and their family will need to identify any additional areas that are of concern to them. They can then apply the information and strategies introduced in this manual to effectively address those issues.

Transition Overview

The high school years are typically a time of changes and challenges. During these years, youth are leaving behind the dependence of childhood and are anxious to step through the door into adulthood. This "in between" stage of high school should be focused on preparing the student for a successful adjustment into the adult world.

As students with disabilities and their families *Begin the Between* period of their youth's educational years, the planning that occurs during this time, known as transition planning, is crucial to the success of the student to fulfill his or her potential. The youth, parents, other family members, educators, human service providers and community members are part of a transition team committed to working collaboratively toward developing and implementing a high school program, individualized to meet the student's needs and desires.

For youth with disabilities and their families, the transition from high school to independent living can be a complicated process. When students are in school, all of their service needs are provided through their school district. Upon leaving the special education system, the services they require to meet their changing needs may become fragmented. The school will no longer be providing these services and young adults must contact several agencies to receive the supports they need. For example, employment support services may be provided by one agency, residential services by another, and income support and medical coverage by another. Application procedures, funding sources, and eligibility requirements differ for each agency.

Because of the complexities of the adult service system, parents, educators, and other professionals have recognized the importance of comprehensive and cooperative planning during high school. This transition planning will help ensure that the necessary services are in place and the student has developed the skills he or she will need to be successful upon graduation from high school.

Because of the complexities of the adult service system, parents, educators, and other professionals have recognized the importance of comprehensive and cooperative planning during high school.

The basic areas of the student's life that the transition plan should address are:

- Future employment. Where will the individual work? How will he or she manage financially?
- Home living. Where will the individual live? What independent living skills will he or she need? How will health needs be met?
- Recreation and leisure. What will the individual do for fun and leisure? How will he or she develop and maintain relationships with friends and family?
- Community participation. How will the individual travel within the community? How will he or she access community services?
- Post-secondary job training. If the individual is interested in pursuing continued education, where will the training occur, and what supports are necessary?

The topics in the remaining chapters represent issues which have been cited by youth, parents and educators as having the most significant impact on the future success of young adults. This guide can help students and families *Begin the Between*, equipped with the knowledge to make their goals and aspirations a reality.

Looking Ahead

The first step in the transition process is to look ahead to the future. This is the time when students and their parents should think about the student's life after high school, and dream about what they want their adult life to be like.

This can be a little overwhelming for youth and their families simply because they may be unaware of the options and support services that are or will be available to them. Another obstacle to looking ahead may be that both parents and students find it difficult to speculate what the student may be capable of accomplishing four to six years down the road. These apparent obstacles should not interfere with beginning to create visions and goals. In fact, not knowing these issues can lead to visions that are positively focused on the youth's desires, strengths, and abilities rather than hampered by negative expectations or perhaps by the limited availability of services.

Youth and their families should allow themselves to take a "sky's the limit" approach during discussions about the future. Parents may be inclined to dismiss their teenager's goals if they sound unrealistic or seemingly unattainable. Instead, they can help the youth to reshape the goals into ones that are realistic. For example:

Son/daughter: "I would like to be a doctor."

Parent: "You have always liked to help others. But remember, doctors go to school for many years and study long hours. You have often said you don't enjoy studying. If that is true, would you consider working in a doctor's office or hospital? Would you enjoy looking into something like that?"

Then bring these goals to the transition team, especially early in the transition process. Team members can provide guidance, information, and training that will help the student reach these goals.

It is important for youth to develop personal visions of where they would like to be and what they would like to be doing in the future. Although parents may feel that they are aware of their teenagers' aspirations, it is important to encourage him or her to express dreams and goals, thereby fostering choice-making abilities and ensuring a transition plan focused on the desires of the student. When dreams and visions are expressed and recorded, then strategizing can begin on what needs to happen so that these goals can be met.

Looking ahead and talking about the future helps the youth, parents, and entire transition team to:

- focus on the individual's hopes and dreams.
- encourage opportunities for the individual to develop preferences that enhance choice-making abilities.
- allow the individual's aspirations to be the driving force behind all transition planning.
- focus on the individual's interests, strengths and abilities, and build on his or her potential.
- focus on accessing opportunities in the community, or creating new ones, to help the individual reach his or her goals.
- focus on building relationships through increased community involvement.
- ensure that goals remain responsive to the individual's changing interests and abilities.

It is important for youth to develop personal visions of where they would like to be and what they would like to be doing.

Parents can use the following questions to guide discussions with their son or daughter about the future, as well as what activities could take place now in preparation for the future. If the student has limited verbal skills, parents can answer these questions based on their knowledge of their son or daughter.

Employment

What kind of jobs have you done that you really enjoyed? These jobs could include home responsibilities, school duties, neighborhood jobs, etc. Think about all the types of "jobs" you do that you like doing and do well. For example, shoveling snow, folding clothes, washing dishes, working with children, woodworking, organizing files, etc.

List choices: _____

_____

_____

_____

Are there jobs or tasks that you have not ever done but would like to learn how to do? For example, washing the car, painting your room, vacuuming, making hamburgers at a restaurant, etc.

After thinking about what types of jobs you would like to do or learn to do, think about what kind of surroundings you would like to be in. For example, do you like to be indoors or outdoors, around lots of people and noise or in a quiet secluded area, etc.

(This question is important for people who are particularly uncomfortable or unproductive in certain types of environments. It would be an important factor to consider when beginning to explore employment training opportunities.)

List choices: _____

_____

_____

_____

You have listed what you like to do and what kind of surroundings you like to be in. Now think about places of employment where you could do what you like to do in the type of surroundings you like. For example, you might have said you like to care for children and be around many people. Places of employment that might fit these choices are a latch-key school program, a park and recreation program, a nursery school, a day-care program, etc.

List choices: _____

_____

_____

_____

Residential

Where would you like to live after you graduate from high school? For example, with family members, in your home town, in the town where a friend lives, in a large city, in a small town, etc.

List choices: _____

_____

_____

_____

Who would you like to live with? For example, your best friend from high school, nobody, with yourself or have a room to yourself, with your sister – you could care for her children, etc.

List choices: _____

_____

_____

_____

What kind of place would you like to live in? For example, a house in the country, an apartment in the city on a bus line, etc.

List choices: _____

_____

_____

_____

Independent Living

What kinds of things do you do to help out around the house? For example, make your bed, pick up your room, help with meal preparation, etc.

List answers: _____

_____

_____

_____

What do you think you need to learn to be able to live more independently in the future? For example, cook a meal, do laundry, make doctor's appointment, etc.

List answers: _____

_____

_____

_____

Are there new things you would like to learn how to do? For example, play a musical instrument, play basketball, try new recipes, etc.

List answers: _____

_____

_____

_____

Recreation / Leisure

What do you like to do for fun? For example, listen to music, play board games, go to the mall, etc.

List answers: _____

_____

_____

_____

Are there any new places that you have not been to that you would like to visit? For example, the new shopping center, a museum, the zoo, a particular restaurant, the beach, etc.

List answers: _____

_____

_____

_____

After parents and youth have discussed some long-range visions, together they can begin a plan for the future by writing one goal under each category, followed by a first step toward reaching that goal. This information can be shared with other family members, school personnel, service providers, and community members.

The more people who are aware of these goals, the better the cooperative effort can be in achieving them. Keep in mind that these goals will change as further discussions are held, goals are met or modified, and the transition process unfolds.

EMPLOYMENT

GOAL: _____

_____

_____

First step: _____

_____

_____

INDEPENDENT LIVING

GOAL: _____

_____

_____

First step: _____

_____

_____

RESIDENTIAL

GOAL: _____

_____

_____

First step: _____

_____

_____

RECREATION/LEISURE

GOAL: _____

_____

_____

First step: _____

_____

_____

Program Planning

A truly successful and meaningful transition process is the result of comprehensive team planning that is driven by the dreams, desires, and abilities of the youth and enhances not only the youth's participation in school but his or her home and community living, as well. A program plan provides the basic structure for preparing an individual to live, work, and play in the community, as fully and independently as possible. As in all aspects of life, the more transition planning that takes place ahead of time, the better prepared youth and their parents will be when decisions need to be made and action must be taken.

Since 1987, a transition plan has been a required component of the Individualized Education Plan (IEP) for Minnesota students no later than age 14, or 9th grade. Federal legislation now requires transition planning in all states for students 16 and older, and can be provided as early as age 14 if the planning benefits the student.

Transition services must be based on the student's needs, taking into account his or her preferences and interests. The services should include instruction, community experiences, the development of employment and other post-school adult living objectives, and, if needed, training in daily living skills and access to functional vocational evaluations. All of these services must be given in a manner that recognizes the student's cultural background and is sensitive to his or her native language, if other than English.

Schools are required to invite students to participate in their IEP meetings whenever transition services are considered. Transition services are a required component of IEPs for students during their transition years, and, therefore, those services are routinely discussed at IEP meetings for students age 14 and older. If the student does not attend the IEP meeting, school personnel must take steps to ensure the student's preferences and interests are considered.

The best transition plans are those that help the student achieve his or her dreams and aspirations. To ensure this, include the student in all aspects of planning and goal setting, and encourage his or her participation at IEP meetings. This participation will help keep all team members focused on the student's individual needs and desires. It will also help the student develop his or her own decision-making abilities and self-advocacy skills.

By being proactive and increasing your knowledge and awareness of transition issues, parents and students can become powerful members of the transition team.

Advance preparation can assist students and their parents throughout the transition process and help contribute to a comprehensive transition plan by providing a direction for goals and objectives. By being proactive and increasing their knowledge and awareness of transition issues, parents and students can become powerful members of the transition team.

In order for the IEP to appropriately meet the student's transition needs, both parents and school personnel must assess the student's abilities, skills and interests. The school accomplishes this through diagnostic assessments, evaluations and informal observations. Parents can do it through their day-to-day knowledge of their son or daughter and conversations with him or her about future goals. (The previous chapter on Looking Ahead can be very helpful.)

Parents and students should consider the following points when beginning the transition process and preparing for or participating in an IEP meeting or transition staffing:

- Ask your teenager what he or she would like to do with his or her life. What are his or her dreams, goals, etc? Incorporate the responses into all aspects of transition planning. If your son or daughter is non-verbal or has difficulty communicating these thoughts, use your knowledge of him or her to make sure transition plans reflect likes, dislikes, etc.
- Know your son's or daughter's needs, abilities and skills. Be familiar with how much assistance he or she needs or does not need to accomplish tasks.
- Know what outcomes you and your teenager want. Bring suggestions to meetings on what actions you feel are needed to meet or move toward goals in the transition plan.

- Encourage your son or daughter to attend the IEP meeting. He or she will be invited. Together, prepare for the meeting.
- Encourage self-advocacy skills for your son or daughter. Have the staff direct questions to your teenager.
- Know what programs, services, accommodations or modifications you and your teenager want. Be clear on the transition needs or issues of your son or daughter.
- Determine who will be responsible for what on the transition plan. Ask for specific timelines.
- Decide whether educational and transition programs should emphasize practical or academic goals or a combination of both.
- Become aware of community-based training opportunities your school provides. Parents and their son or daughter should decide how much the student should participate in those activities currently, as well as in the future.
- Request a copy of your son or daughter's daily schedule each quarter or semester.
- Request information on all classes available to students so your son or daughter can participate in the class selection and scheduling process.
- Determine how your son's or daughter's educational and transition program could be more integrated into regular programs.
- Learn who will attend the IEP meeting. Become familiar with the roles and functions of team members.
- Arrange for a family member, friend or advocate to accompany you and your son or daughter to planning meetings for support or note taking, if needed.

In general, becoming familiar with adult service systems or agencies now will help your son or daughter in making decisions that will impact on the future.

A final tip: Start thinking about what needs will exist regarding your teenager's legal status once he or she is 18. If your son or daughter is not able to make informed decisions about major issues (medical treatment, living accommodations, financial arrangements, etc.), your family may want to learn more about guardianship or conservatorship. By learning as much as possible about these options, your family can ensure that your son's or daughter's rights are protected, while allowing him or her to retain as much independence as possible.

Planning notes

Case Management

The delivery of case management services varies from state to state. In Minnesota, the Department of Human Services provides community support services for persons with mental retardation (IQ 70 or below) or related conditions. Related conditions may include cerebral palsy, epilepsy, autism, Prader-Willi Syndrome, or other conditions (other than mental illness) which substantially limit major life activities. It's important to learn the case management process in your state.

As a young person moves into the world of adult services, a case manager provides the funding, when available, and access to services which aid in the transition process. Through the development of an Individual Service Plan (ISP), the case manager, with input from the individual and their family members, identifies the services that are needed and is responsible for coordinating and monitoring the services provided.

The case manager should participate in the transition process by attending Individual Education Plan (IEP) meetings and monitoring the delivery of services and progress made on transition goals. He or she can assist the student and family members in making decisions about planning for and obtaining the services needed both now and in the future.

Support services that may be available from the county

- Waivered services
  Respite care
  In-home supports
  Minor adaptations to the home
  Supported Living Situation
  Supported Employment
  Day Training & Rehabilitation
- Residential services
  Semi Independent Living Services (SILS)
  Intermediate Care Facilities for
  Persons with Mental Retardation
  Foster Care
- Health Care Services
  Personal Care Attendants
  Children's Home Care Option
  Occupational Therapy, Physical Therapy,
  Speech Therapy
- Family Subsidy
- Transportation

Case management process

1) A family applies for a county case manager (applications available at local county social service office).
2) A case manager is assigned within 10 days after the application is received by county.
3) The case manager arranges for a diagnosis to determine the person's eligibility for services within 35 working days.
4) An assessment is completed to determine the person's abilities and needs.
5) The case manager works with the family to identify services needed, and determines how and when services will be obtained or developed if not available.
6) The case manager works with the family to develop an Individual Service Plan (ISP), which designates needed services and defines goals and objectives.
7) The case manager monitors these services by visiting the person at his or her service site at least twice yearly for most services.
8) The case manager and the family review the ISP annually for appropriateness and updates as needed.

If case management services are denied, reduced, terminated, changed without the family's consent, or if the individual or his or her family is not satisfied in any way, they have the right to request a conciliation conference or an appeal hearing.

Planning for ISP review meeting

Preparing for an ISP Review can be a complicated process. By discussing with your son or daughter changes that have occurred for him or her since the last review meeting, you can compile important information prior to the meeting and be prepared to address those issues with your County Case Manager and service providers.

Issues to consider prior to the ISP meeting:

1. Discuss with your son or daughter what successes or progress have occurred since the last ISP review.
   - List positive changes that your son or daughter feels have occurred. _____
     _____
     _____
   - List successes or progress that family members have observed. _____
     _____
     _____

2. Discuss with your son or daughter problems or concerns that have arisen for him or her.
   - List problems or concerns that your son or daughter feels have occurred. _____
     _____
     _____
   - List obstacles that parents and others have observed.
     _____
     _____
     _____

3. List additional supports or services that would help resolve any of these problems or concerns.
   _____
   _____
   _____

After considering the above questions, if some issues could be resolved with additional support from the county, it might be helpful to contact your case manager in advance of the meeting. Your case manager may then be able to get approval for funding (if available) for these services, and implementation of them can be discussed at the meeting.

ISP Participants

County case manager

Name _____ Phone _____

Address _____

_____

Meeting date _____

People invited to meeting

Name	Title	Date
_____	_____	_____
_____	_____	_____
_____	_____	_____

Meeting notes

Taking notes during the ISP review will help you ensure that all services discussed are included in the ISP. By referring to your notes, you can follow up with your son or daughter's case manager and service providers to be sure they are fulfilling all designated responsibilities.

Employment

One of the most important aspects of transition planning is the preparation of the youth for the world of work. There are a variety of people who are trained to support youth and their family in planning and preparing for employment in the community. These people may include vocational, special and regular educators, counselors from the Department of Rehabilitation Services (DRS), and county case managers. In many schools, Vocational Education programs designed to prepare youth for employment in the community are also available.

Throughout a student's education, there are job-related skills and behaviors, known as PREVOCATIONAL skills, which can be fostered to help him or her be successful in future employment. These skills should be part of early educational planning, and be developed in both the home and school environment. Examples are:

- physical stamina
- promptness
- problem solving
- hygiene
- ability to accept criticism
- ability to follow directions
- independence in completing assigned tasks
- ability to establish social relationships with co-workers

Vocational Education Planning

Upon graduation from high school, many individuals may choose to pursue continued employment training in a post-secondary institution; others will choose to begin working right away. In either case, a carefully designed vocational program in high school will help prepare the youth for a job that will be both challenging and rewarding.

A comprehensive vocational plan is one that will assist the student to develop the skills needed to find and keep a job after graduation. High schools offer vocational education programs that are designed to prepare students for employment. In schools that offer a vocational work experience program for students with special needs, the primary member of the vocational team should be the work experience coordinator, a teacher who is vocationally licensed. This individual, along with other teachers, will work with students to develop vocational goals that reflect their skills, abilities and vocational needs. If a school does not have a vocational education program, the student's special education teacher is responsible for developing the student's vocation goals.

Youth with disabilities are entitled to certain employment-related services. The basic services that they should receive during high school are:

1) A vocational assessment of their interests and abilities.
2) Special services, including curriculum modifications that facilitate success in vocational programs.
3) Guidance, career counseling and career development activities.
4) Counseling services to ease the transition from school to work.

Division of Rehabilitation Services (DRS)

Another important member of the transition team is a counselor from the Department of Rehabilitation Services (DRS). This person will work with the team to help plan for the student's future employment needs. DRS is an agency that primarily serves adults; however, it is important to involve the counselor during the transition process so when the student graduates and enters the work force, the supports are in place that will allow him or her to be successfully employed. To receive services from DRS, an individual must meet certain eligibility requirements.

To qualify for DRS services:

1) The individual must have a physical or mental disability which presents difficulties or barriers to employment.
2) There must be a good chance that DRS services will help him or her get and keep a job.

The role of DRS is to help persons with disabilities find employment. The services that DRS buys must be employment related. The types of services DRS provides include:

* medical, psychological and vocational evaluations;
* transitional and supported employment;
* assistance in adapting work settings;
* assistive aids to increase a person's ability to work, such as communication boards or motorized chairs.

If the teacher has not made the referral by this time, parents can request that contact be made, or contact DRS directly and request their involvement. If the student has more challenging employment needs, a DRS counselor can become involved in the planning process as early as age 14. By becoming involved during the transition planning process, your DRS counselor can become familiar with the student, his or her employment goals and his or her future service needs. The counselor may be able to arrange services which can supplement the vocational program the school is providing to help make a smooth transition into permanent employment.

DRS services are time-limited. For example, the agency will provide job-placement services, and to ensure the person with a disability is satisfactorily employed, will provide follow-up services for at least 60 days and up to 18 months after the initial job placement. If an individual requires ongoing support beyond this period, the county human services agency is typically financially responsible for the services. The county will purchase these supports from providers of employment services. Because the county must agree in advance to provide this long-term support, the case manager should be involved in any long-range employment planning along with the DRS counselor.

If, in the future, the person with a disability once again needs assistance to retain his or her current employment, find a new job, or reestablish a vocational program, his/her file can be reopened by contacting the previous DRS counselor. In some cases the person may need to reapply for DRS services.

Types of employment

Individuals who desire to enter the work force upon graduation should start planning for employment as early as possible. The person with a disability and his or her family members need time to determine what kinds of work are best suited to the interests and needs of the individual.

There are two aspects to employment that are extremely important to consider: finding a job and keeping a job. Individuals may require little or no help with one or both, or they may require a great deal of help.

Help finding a job comes from the Vocational Rehabilitation Agency, and, at times, from the county social service agency. These agencies often purchase this help from companies that specialize in finding employment for adults with disabilities.

How much help does your son or daughter need finding a job?

No help ..... Some help ..... Very much help

Employment in which persons need long-term or ongoing help to keep a job is called supported employment. Supported employment is a job with pay at a business in the community. Help for the individual is provided by the same companies that specialize in finding employment for adults with disabilities. They provide a job coach to give help directly to the individual with disabilities. In some cases the job coach provides assistance to the managers and co-workers so they can assist the employee who has a disability. This is called supported employment with natural supports.

How much help does your son or daughter need keeping a job?

No help ..... Short-term help ..... Long-term help

The amount and kind of help that is provided to find and keep a job should be based on the needs of the person with the disability. No person should be denied the opportunity for employment by a vocational rehabilitation or social service agency because of the severity of his or her disability.

As the team begins to look at agencies that provide employment services, the following questions can help you learn more about the provider. The questions will also help you assess the school or agency's ability to provide services that will meet the youth's desires, needs and abilities.

1) What types of jobs are available?

2) How do you select a job for an individual?

3) Where are the actual job locations? Do you provide individual or group placements?

4) How do you promote integration?

5) What are the average wages of employees? What is the average number of hours worked per week?

6) What type of support do you provide?

7) Is transportation provided? What type and by whom?

8) What are the average benefit packages available to employees?

9) What provisions do you have for employee and parent or family input?

Planning notes

Residential Options

Part of the transition process for a young person with a disability is to start discussing where they want to live after graduation from high school. Will they continue to live at home? Will they move into their own apartment? Will they move into the community in a supported living situation? If the goal is to move into the community, planning for this move is necessary so that both the youth and his or her parents can learn about all the options available, and the youth can learn the skills necessary to live as independently as possible.

As the youth and his or her family begin to think about the future, the following are some of the areas that they will want to consider as they begin to identify the type of living situation that would be most appropriate.

- Supervision – In what areas of daily living will the individual need continued supports?
- Companionship – Will roommates be peers with or without disabilities? How will integration in the community be achieved?
- Location – What is the proximity to family members, friends, work, church, synagogues, other activities?
- Transportation – Will the individual learn to drive a car? Are bus routes, work, recreation nearby?
- Support services – How will physical therapy, medical, dental, other health needs be met?
- Physical Environment – Is the location barrier-free? How will assistive technology needs, telephone device for the deaf (TDD), etc. be met?

There are a variety of residential options available for adults with disabilities. After considering all of the issues that affect the young person's level of independence, the family can begin to explore the choices that are available. Students with disabilities and their families will want to learn as much as possible about the residential options available in their own state to choose the one that will best match the student's potential.

Rent subsidized apartment
Individuals who have the skills necessary to live independently may be interested in renting an apartment of their own. For people on a limited income, rent subsidies, such as Section 8 certificates, are available through your local housing department. These subsidies allow people on a limited income to live in an integrated environment in a regular apartment building.

Semi Independent Living Services (SILS)
Many individuals who might otherwise live in a more restrictive setting are able to live in the community with supports. SILS is a service which is available through the county, and is provided to persons with mental retardation or a related condition in their place of residence. SILS provides training and counseling in specific areas of independent living such as financial management, grocery shopping, meal preparation or medical issues, while allowing the person to maintain their independence.

Personal Care Assistant (PCA) Services
People who need assistance for physical health or care issues can benefit from PCA services. Personal care services may aid a person in areas such as medication administration, bladder care, range of motion and positioning exercises. The services are available through Medical Assistance, and are managed by the person with a disability.

Adult Foster Care
For people with disabilities who want to live in a family setting but are unable to live independently, adult foster care provides them an opportunity for full integration in the community while living in a safe environment. The person with a disability can live with a family or individual foster care provider, licensed by the county, who will provide supervision and personal care while allowing the person to maintain a great deal of independence.

Private Ownership
Many people prefer the security of private ownership over renting an apartment or living in someone else's home. If a person with a disability or their family is able to purchase a home, arrangements can be made with the county to secure services to be provided in the home. One benefit of the arrangement is the consistency of the home environment for the person with a disability. Staff turnover will result in a minimum of disruption for people in their own home.

Supported Living Services (SLS)
People with mental retardation or a related condition who need additional assistance to live in the community may live in an SLS. An SLS is a home where no more that six adults with similar disabilities live. The structure of the home includes paid staff who supervise the residents of the home and provide assistance and training with daily living skills. Services are funded through waivered services and arranged by the county case manager.

Intermediate Care Facility for Persons with Mental Retardation ICF/MR
An ICF/MR is a group home for people who require 24-hour supervision. People who live in an ICF/MR are supervised by paid staff who provide daily care and help the residents develop daily living skills. These services are also paid for through the medical assistance waiver and arranged for the county social worker.

If the person with a disability and his or her family decides that a supervised residential setting is most appropriate to meet the individual's needs, they will want to investigate the programs that offer these services. Following are some issues that should be considered when choosing a provider of residential services.

- What are the eligibility requirements? How is the home licensed and who ensures that it is fulfilling all of its requirements?

- How is the home integrated into the community? Is it located near bus lines, shopping, and recreational interests?

- How many staff are available in the home, what hours do they work, what are their qualifications, and how are they trained? Are staff available if someone needs to stay home from work or an activity due to illness?

- Do persons living in the home have individual program plans that increase choice making, independent living skills, self esteem, and recreation/leisure participation?

- Does the home have a structured daily schedule? Does it allow for personal choice of activities and private time?

- Do people who live in the home have opportunities to participate in activities of their choice? Is transportation provided to scheduled and unscheduled activities?

- How are challenging behaviors handled, and how is the family included in the behavior plan or intervention?

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- How many people live in the home? Are they provided privacy and choices with regard to their personal space and property? Do they have a choice of having their own room or sharing a room with another individual?

- What is the condition of the home, and of people living there? Does the home have age appropriate furnishings and supplies? Are individuals dressed in an age appropriate manner, in clean clothes with good personal hygiene? Do they seem happy?

- How is medication stored, monitored and given? Are medical services provided on a regular and as-needed basis? Who provides medical services?

- Who manages the resident's money? Do the residents have choices with regard to how their personal finances are spent?

- How do the staff interact with the people who live in the home? Do staff participate in activities of the home as peers, joining meals, recreational activities, etc.?

- What are your son's or daughter's feelings about the home? Impressions? Likes? Dislikes?

- What's your feeling about the home? Impressions? Likes/ dislikes?

Preparing for Transition to Adult Health Care Services

While preparing for independence, it is important for adolescents with disabilities to consider assuming some responsibility for their own health care. As young adults with disabilities seek services in the adult health care system, they find they must acquire new information and develop different skills. The health system expects young adults to make decisions about their own health care and independently coordinate services. Parents and adolescents struggle with meeting these demands and finding appropriate resources as they seek health care in the community.

Transition Health:

- Focuses on learning what skills are needed to assume responsibility for health care.
- Focuses on issues of sexuality and reproductive health.
- Builds communication skills with health professionals.
- Promotes self advocacy in health care.
- Identifies health care financing resources.
- Provides an opportunity to plan transition health goals.

Transition Health planning consists of:

- Identifying those health-related skills the adolescent can perform independently.
- Identifying community support and resources to help the adolescent assume some responsibility for his or her health care.

Is your son or daughter ready to manage his or her own health care?

Use the following questions to guide your discussion on health care with your son or daughter. These questions will help you gain some insight into how your son or daughter feels about being responsible for his or her own health care.

I worry about my health.

My parents always take care of all my health needs.

I would like to know more about my illness or disability.

I would like to be responsible for taking my own medications and following my own medical plan.

It is easy for me to talk with my doctor.

I feel I have little or no control over my illness or disability.

If I follow my doctor's orders, my doctor will be pleased with me.

I would like to speak with my doctor alone during visits.

I would like to go to the doctor by myself.

Sometimes I get embarrassed if I have to take my medications in front of my friends.

If I follow my medical plan and take my medications, my health is usually good.

My health needs will affect my future.

Discussion Notes

Health Care Skills

Here is a list of health care skills to consider in planning for health care in the community. Which skills does your son or daughter perform independently? Which skills will he or she need specific supports to perform? What support and resources are available in your community? Consider writing some health goals in your son's or daughter's Individual Education Plan (IEP) and Individual Service Plan (ISP), and detailing health information in the letter of intent, discussed on pages 36, 37 and 39.

Skills / Abilities	Current Skill Level	Desired Skill Level	Resources/Persons who can help your son/daughter gain this skill
Describes chronic illness or disability			
Understands implications of chronic illness/ disability on daily life			
Accesses medical records, diagnosis information, etc.			
Prepares and asks questions for doctors, nurses, therapists			
Knows medications and what they're for, or carries information in wallet			
Is responsible for following own medical plan			
Is responsible for doing own treatments			
Gets a prescription filled/refilled			
Calls to schedule own medical/dental appointments			
Keeps a calendar of medical appointments			
Knows transportation system to medical office			

Skills / Abilities	Current Skill Level	Desired Skill Level	Resources/Persons who can help your son/daughter gain this skill
Knows height, weight, birthdate, or carries information in wallet			
Knows how to use and read a thermometer			
Knows health emergency telephone numbers, or carries information in wallet			
Knows medical insurance numbers, or carries information in wallet			
Knows about medical insurance coverage			
Obtains sex education materials/birth control/ family planning information as needed			
Knows about general health maintenance			
Knows about how drugs/alcohol affect disability/illness			
Makes contact with appropriate community advocacy organizations			
Takes care of own menstrual needs and keeps a record of monthly periods			
Has considered the need for a health advocate			
Has identified a physician for adult care			
Knows how to hire and manage a personal care attendant			

Estate Planning

Through proper estate planning, parents can improve the quality of life for their son or daughter by leaving funds to cover their supplementary needs, while not threatening their government benefits.

People with disabilities often rely on Medical Assistance (MA) and Supplemental Security Income (SSI) to provide for their basic income needs. Eligibility for either program, however, is based on a person's financial resources. Benefits from the government programs are lost when a person exceeds the eligibility limits.

How parents plan their estate, therefore, can have a great effect on the quality of life for their son or daughter with a disability. Proper planning can make sure that any financial provisions made by parents are used to supplement their child's care, not replace current funding for programs or services. A comprehensive life plan is essential to ensure that a son or daughter with a disability will live in a comfortable environment, receive competent care, and have funds to maintain a comfortable lifestyle during their parents' lifetime and after.

This plan will provide the economic security to allow the person with the disability to maintain his or her quality of life while not jeopardizing governmental benefits by receiving a direct inheritance.

To ensure that the plan is comprehensive and that legal documents are prepared appropriately, the family should consult a team of professionals who are familiar with the legal issues involved. This team would typically consist of an estate planner for overall coordination, an attorney for preparation of legal documents, and a certified public accountant to review tax and financial considerations. Whether parents consult an estate planning agency or assemble the team individually, there are several steps in the process which will ensure that a comprehensive Life Plan is designed.

Basic Planning Steps *

1) Prepare a life plan. Develop a vision of what you and your son or daughter would want for their future. Examine all areas of their life, list all the options that are acceptable, and prioritize them in order of preference (see life planning table on next page).
2) Write a letter of intent. This document should provide clear guidance to your successor(s) regarding your hopes and desires for the future of your son or daughter, and include information your successor will need about the daily care of your son or daughter.
3) Choose a guardian, conservator or advocate. This is the person(s) who will ensure that your wishes are carried out.
4) Determine the realistic cost of your plan. Working with a financial planner, determine how much it will cost to carry out all aspects of your plan over the lifetime of your son or daughter.
5) Select a combination of resources that will guarantee adequate funds for the person's lifetime. Now that you know how much it will cost to carry out your wishes, where will the money come from?
6) Working with your attorney, prepare carefully worded Last Will and Testaments. You must exclude your son or daughter with a disability by name, so he or she does not receive a direct inheritance and jeopardize governmental benefits.
7) Establish a Living, Special Needs Trust to manage the resources, protect your son or daughter's governmental benefits, and provide supplemental financial assistance.
8) Choose a number of successor trustees to manage the trust funds in the future. The person(s) you choose should be individuals you trust to carry out your wishes, and who care about your son or daughter with a disability.
9) Place all estate planning documents together in a special binder and store in a secure place.
10) Hold a meeting with your successors to review the plan. Give everyone a copy of your letter of intent, explain how your plan is going to work, and let everyone know where you will be keeping the binder.
11) Review your plan at least once a year. Update your letter of intent and modify the legal documents as needed.
12) Relax. You have done all that you can to make sure that your son or daughter will be well taken care of.

* Adapted with permission from "Planning for the Future," Estate Planning for Persons with Disabilities, Bloomington, MN.

Life Planning

To begin the life-planning process, think about the areas of your son's or daughter's life that will need planning. Write down the most desirable future situation for him or her in each of these areas. Also list the things that should be provided to enhance the quality of that area of their life. Because of the cost, many of the amenities that you will want your son or daughter to continue receiving will need to be included in your financial plan. For example, the residential arrangement you envision for your daughter may be living in a home with two or three other people with similar disabilities. To enhance her quality of life in the home you may want to ensure that she can continue to visit her beauty shop each month and is able to supplement her wardrobe with new clothes occasionally. You may also want to ensure that she is able to give gifts to friends and family on special occasions. To ensure that these amenities can be provided even after you are gone, you will need to allow for them as you do your financial planning, and include them in your letter of intent to provide guidance to your successor.

Residence	Education	Employment	Guardian/advocate	Social
1.	1.	1.	1.	1.
2.	2.	2.	2.	2.
3.	3.	3.	3.	3.
4.	4.	4.	4.	4.
Medical Care	Behavior management	Religious	Trustee(s)	Final arrangements
1.	1.	1.	1.	1.
2.	2.	2.	2.	2.
3.	3.	3.	3.	3.
4.	4.	4.	4.	4.

Participants in Life Planning

Because each member of the Estate Planning team performs a specific function, logging contacts made with each individual will assist you in coordinating the planning effort and allow you to follow up on progress between planning meetings.

Role	Name/Organization	Phone #	Date of Contact	Action to be Taken/Follow-up
Estate Planner				
Attorney				
Accountant				
Future Guardian/ Conservator				
Other Parties/ Family Members				

After you have determined the most desirable future for your son/daughter, with input from all of the family, the next step is to compile this information into a letter of intent. The letter of intent should contain vital information about both the history of your son or daughter, and the lifestyle that should be provided in the future. Using the previous section on life planning, parents can guide their successor in future decision-making by giving specific examples of ways the money in the trust should be utilized.

Some issues that you may want to address in your letter of intent include:

- How the day-to-day needs of your son or daughter will be provided.
- How any behavioral, medical or daily care needs are most effectively addressed.
- What personal items, clothing, gifts, vacations, etc., will be provided by the special-needs trust to supplement his or her governmental benefits.

The letter of intent should be updated periodically to keep pace with the changing needs and future desires of your son or daughter. It is the guiding tool that you will use as you work with your estate planning team to complete the remaining steps of developing a Life Plan.

Planning notes

Final Thoughts

While the transition from high school to adult life is a complex time for all students, it can be especially challenging for young people with disabilities. The goal of this period of planning is to help the student enter his or her adult life prepared to successfully meet the challenges that lie ahead.

This manual has focused on the important issues facing students and their parents during the transition years. Planning together, networking with others in the community and using an assertive approach to problem solving will enable family members to achieve their goals.

The transition from high school to community living, between childhood and adult life, cannot be described in terms of a finite period – one with a beginning and an end. Rather, the young person's goals and visions for the future will continue to evolve during this period and throughout their lifetime. Life is a series of transitions, beginnings and betweens, and the quality of life depends on how all members of the family learn to prepare, adapt and cope with these changes.

About PACER

PACER Center is a statewide nonprofit organization that serves families of children and adults with disabilities. PACER works through the coalition efforts of families representing 19 disability organizations. The Center's mission is to expand and improve opportunities that enhance the quality of life for children and adults with disabilities.

Staffed primarily by parents of youth with disabilities and individuals with disabilities themselves, PACER carries out the philosophy of "Parents Helping Parents" through workshops, individual assistance, and written information.

Other resources related to education services, transition, and employment for people with disabilities are available from PACER Center. Among them are:

- ***Parents Can Be the Key***, a 32-page handbook that describes special education laws and procedures.
- ***A Guide for Parents to the Individual Education Program (IEP) Plan***, a booklet that helps parents of children with disabilities work with schools to address each child's special needs.
- ***Opportunity Knocking: The Story of Supported Employment***, an overview of the basics of supported employment.
- ***Supported Employment: A Step by Step Guide***, a resource manual to assist individuals and groups seeking supported employment by explaining how the adult service system works, describing "best practices" in supported employment, providing tips for individuals seeking supported employment, and suggesting how to organize to bring supported employment into a community.
- ***Health Care and Transition Planning***, a handbook to assist families of adolescents with chronic illness and disabilities in transition health care planning.
- ***A Guidebook for Parents of Children with Emotional or Behavioral Disorders***, a resource that provides helpful information to parents about emotional and behavioral disorders (EBD), brief descriptions of common diagnoses and therapies, educational rights, a model for developing community-based services, and funding sources.
- ***A Bibliography of Supported Employment and Transition Resources***, a compilation of annotated journal articles, maunscripts, books, and audiovisual materials.

To order a publication list or to inquire about any of these publications, call or write:

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